

Cancer Reporting and Register Program

By ANITA K. BAHN, B.A.

Reporting and registration of cancer illness can serve a twofold purpose in cancer control—provision of services to patients and collection of statistics needed for program planning. To further these aims, a pilot cancer morbidity reporting program has been operating in four Maryland counties during the past 3 years under the cooperative direction of the Maryland State Department of Health and the National Cancer Institute, Public Health Service. The first detailed statistical report on cancer case information derived from the program will be published later as a monograph. This paper summarizes the project findings and outlines the techniques utilized in obtaining the data.

Procedures

A detailed description of reporting and register procedures in Maryland appears in the Manual on Cancer Register, Maryland State Department of Health (September 1, 1951). These procedures are described briefly here.

Reporting

Every physician, hospital, clinic, and pathological laboratory in a county is requested to report all cancer cases, when first seen, to the county health department. Information is also obtained on cancer patients who are residents of a county but are diagnosed and treated in out-of-county facilities. This information is

Mrs. Bahn, formerly a biostatistician at the National Cancer Institute, is now a biostatistician at the National Institute of Mental Health of the National Institutes of Health, Public Health Service.

obtained principally as a result of report interchange with other State health departments. To further augment available information, death certificates and other health department records are routinely searched for unreported cancer cases. A report is then requested from the appropriate medical agency.

A "visible" register card file serves not only as the local health department record of cancer case information but also as a guide for nursing supervision and follow-up. Signals indicate (a) cases under public health nursing care, (b) the nursing district in which every registered case resides, and (c) the month a follow-up report is to be requested.

For each registered case, follow-up information is requested periodically from the supervising physician or clinic. Follow-up is semi-annual during the first year after the case is reported and annual thereafter, throughout the patient's life. This procedure provides information concerning the progress and outcome of each case, in addition to stimulating medical follow-up of the cancer patient.

Public Health Nursing Service

Both the initial case report and follow-up forms include the question: "Do you wish public health nursing service for your patient? If Yes, a public health nurse will call you for instructions." This item facilitates the provision of service to cancer patients and also serves as a continuing reminder to the physician of the service aspects of the program. In many instances, for example, the public health nurse has been called upon to visit a patient who fails to keep an appointment and to help arrange his return for treatment or check-up.

Summaries and Analyses

Reporting record cards and simple administrative reports prepared by the local register clerk help to keep local and State health department personnel informed of register activities.

Detailed tabulations and analyses are prepared in the State Department of Health, where special tabulating facilities and personnel trained in statistical techniques are available.

The State records consist of a single alphabetic file of case folders, divided into active and inactive cases. Each folder contains all the reports received on a case. In addition, for each calendar year there is a file of punched cards, one card for each case active during the year. These cards may be used for annual tabulations, or cards for more than 1 year may be combined for analyses requiring a large number of cases.

As a result of such procedures as the use of the same code sheet for a 10-year period and the coding of information (other than new cases) only once a year, practically-all coding and punching is completed in a relatively short period of time. More clerical time is therefore available for such tasks as assisting in the preparation of analyses of the data. After all, without adequate summaries of the cancer experience reported, the data in the files serve no useful purpose.

Staffing Requirements

For the successful operation of a cancer register of the kind and scope described, the services of the following types of personnel are required: in the local health department, the county health officer, public health nursing supervisor and staff nurses, and a secretary or clerk; in the State health department, a medical officer, public health nursing supervisor or consultant, statistician, clerical personnel, punch card operators, and machine tabulating personnel.

It is not necessary that these services be full-time. Each type of person enumerated, however, has special skills to contribute to the efficacy of the program. The assistance of the county health officer, county and State public

health nursing supervisors, and State cancer control director, for example, although largely advisory, is essential for the guidance and maximum utilization of the register, and the acceptance of the program in the community.

The question naturally arises as to how much time is required to operate a program of this type. It did not seem practical to determine the amount of professional time involved, but it was possible to conduct a 2-month study to determine the number of clerical man-hours required to operate the cancer register program in the local and State offices. The table below indicates that little more than two clerk-days a month (or approximately one-half clerk-day a week) are required to maintain a cancer register in a local health department serving a population of approximately 80,000.

Number of man-hours required per month to operate local cancer register (exclusive of nursing service)

County ¹	County population (1950)	Active registered cases (June 30, 1951)	Man-hours per month to operate register
Harford.....	52, 000	83	6½
Frederick.....	62, 200	228	16½
Washington.....	78, 700	368	16½
Total.....	192, 900	679	39¼

¹Montgomery County, with a population (in 1950) of 163,700 and 427 active registered cases on June 30, 1951, is not included, since the register work performed in this county during the 2 months of the time study was atypical of routine procedures.

Although, in comparison with other local health department operations, relatively little time is spent on cancer register activities, it is interesting to see how this time is accounted for by type of cancer register activity. The total 39¼ clerical hours per month for cancer register work in the three counties is distributed as follows:

1. Receipt and posting of current reports and information to register card, and register services to public health nurses, such as transcribing information from cancer register card to nursing service record for cases newly opened to service—19½ hours, or 50 percent of the total time.

2. Sending requests for case reports to medical agencies known to have seen an unreported case—8¾ hours or 22 percent.

3. Sending requests for follow-up reports to medical agencies—7¾ hours or 20 percent.

4. Preparing administrative reports—3¼ hours or 8 percent. (This figure is somewhat higher than a true monthly average since a semi-annual report was prepared during one of the two months in which clerical time was recorded).

As reporting improves, the 8¾ hours (one-fifth of total register time) required to request case reports will be reduced. Differences between the counties in man-hours used in conducting register activities may be attributed in part to different reporting problems in each county.

In the State office, approximately 1⅓ persons are required full time to perform the routine register operations of filing reports, abstracting cause-of-death information, coding basic information for newly reported cases, correspondence, and occasional visits to the counties to discuss reporting and register problems. In addition, it takes 2 persons approximately 6 weeks annually to code current information on cases in the active register (2,000 cases in 1951), exclusive of the time used for preparation of punched cards and tabulations.

The above data illustrate that, from the standpoint of workload, the cancer register procedures developed in connection with this program represent a feasible and practical system of operation.

Statistical Findings

What statistical findings with respect to cancer patients in the four counties have been revealed by this study? Findings of the first 2 years of operation are described in "Cancer Illness Among Residents of Four Maryland Counties, 1948 and 1949," which is to be published by the National Cancer Institute of the Public Health Service. A summary of this report follows.

The estimated total population of the four study counties (Frederick, Harford, Montgomery, and Washington) during 1948-49 was about 340,000, including urban, semirural, and

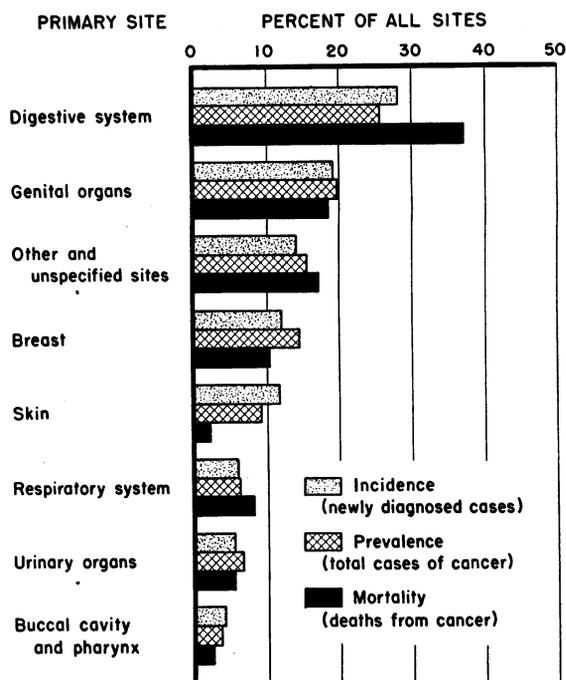


Figure 1. Comparison of cancer incidence, prevalence, and mortality in four Maryland counties, 1948 and 1949.

rural communities of varying sizes. In 1940, one-half of the population was rural nonfarm and one-fourth, rural farm. This is one of the few instances where data are available on cancer illness for an area with a large rural population. Therefore, it is interesting to compare the Maryland data with National Cancer Institute data based upon morbidity surveys of five urban areas (Atlanta, New Orleans, Pittsburgh, Denver, and San Francisco).

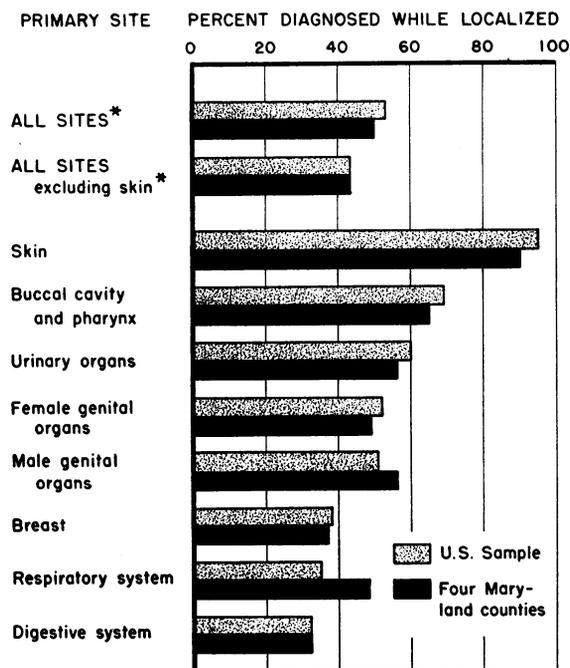
Number and Kinds of Cases

During 1948 and 1949, an average of 650 newly diagnosed cases of cancer was reported yearly among residents of the four counties in the study. Each year a total of 950 persons were reported ill with cancer, and 450 deaths were attributed to this disease. It is believed, however, that a substantial number of diagnosed cancer cases were not reported. Based on the number of registered county deaths and on the ratio of diagnosed cases to registered deaths in the group of five surveyed cities, it is estimated that there was actually a minimum of 1,300 persons ill with diagnosed cancer each year, 900 of these newly diagnosed. In the five surveyed cities, an average of three diag-

nosed cancer cases was found for each registered cancer death, two of which were newly diagnosed. In addition to the cases of diagnosed cancer, there was an undetermined number of undiagnosed cases which will remain undetected until later years.

More newly diagnosed cases of cancer were reported among females than among males during 1948 and 1949 in each county except Harford. A total of 737 cases in females was reported, compared with 600 cases in males (a ratio of 1.2 cases in females to each case in males). Five percent of the reported cases were in nonwhite persons.

The digestive system was the principal site of cancer among both male and female patients who were newly diagnosed (fig. 1). However, cancers of this site were relatively more frequent among males (31 percent of all cases in males compared with 26 percent in females). The skin and genital organs were the next most frequent sites among males; genital organs and the breast, among females. Together, the last two sites accounted for almost half of all cases in females.



*Excludes leukemias and lymphomas.

Figure 2. Comparison of newly diagnosed cancer cases, diagnosed while localized, in four Maryland counties and in United States five-city sample. (Data based on cases for which stage at diagnosis was reported.)

Although some forms of cancer (lymphomas, leukemias, brain and bone tumors) occur frequently among younger persons, cancer is largely a disease of late adult life—70 percent of the newly diagnosed cases were among patients 55 years of age and over. In general, cases in the female were diagnosed at a slightly younger age than cases in males (an average of 60 years compared with 63). This may be explained in part by the predominance of malignancies primary in the genital organs and breast among females. Cancers at these sites occur at younger ages than do cancers that predominate among men (cancers primary in the digestive and respiratory systems, skin, and male genital organs). Incidence and prevalence rates per 100,000 population would greatly assist in the analysis of these data; unfortunately, these rates cannot be determined until a greater proportion of diagnosed cancer cases are reported.

The average cancer mortality rate per year was 133 deaths per 100,000 population in the four counties studied, compared with a mortality rate of 143 for the total United States. The mortality rate was highest in Frederick County (164 per 100,000) and lowest in Montgomery County (115). In part, these differences may be explained by the age composition of the county population. To evaluate the influence of age upon mortality, age-standardized mortality rates will be computed when 1950 population data become available.

Diagnosis, Treatment, Other Medical Care

It appears from the data collected that more intensive case-finding programs are needed to aid in the early discovery of cancer cases. Only half of the newly diagnosed cases were discovered while localized at site of origin (fig. 2). Three out of every ten cases were found after the neoplasm had metastasized to regional tissues, and 2 out of every 10, after remote tissues had become involved. Cancers of inaccessible organs generally went undiagnosed until a late stage. A smaller but still substantial proportion of cancers of accessible sites were also undiagnosed until a late stage. For example, 63 percent of all breast cancers and 51 percent of cancers of female genital organs were diagnosed after metastases had occurred.

Another criterion for adequacy of medical care is the proportion of diagnoses confirmed by microscopic examination. Of the cases newly diagnosed in 1949, 68 percent were confirmed microscopically, about the same percentage as that found in the United States sample of five cities.

Surgery alone was the primary course of treatment for over half of the cases for which information was available. Seventeen percent of the patients received radiation therapy only, while 8 percent were treated by both surgery and radiation. About 2 out of every 10 patients were not treated or received only palliative therapy. In this category were a relatively high proportion of cases of leukemia (75 percent) and cancers of the respiratory and digestive systems (45 and 34 percent, respectively). Nontreated cases were reported among these cancers even if discovered while localized. Some of these cases, however, may have received treatment which was not reported.

The average duration of first hospitalization for newly diagnosed cancer cases was 17 days. The total number of days of first hospitalization for cancer for patients residing in the four counties is estimated to be between five and six thousand yearly, including in-patient days in out-of-county hospitals. If all hospitalizations for cancer cases during a year are considered, regardless of the frequency of hospitalization or the date of diagnosis, one may estimate a total of 9,000 hospital days a year for resident cancer cases.

Another important index of the quality of medical management of cancer cases in a community is the continuity of medical care. Continuous medical supervision of cancer cases is needed to assure that a reappearance of cancer symptoms will be detected promptly. However, 83 persons ill from cancer in 1948 were not reported seen by any medical agency in 1949. Some of these patients were ill when last seen by a physician and had not returned for further treatment. Although one-fourth were cases of skin cancer, cases no longer under medical supervision were reported for cancers of the breast, digestive system, and other sites with relatively poor prognosis.

Since the performance of an autopsy is considered desirable for the confirmation of the

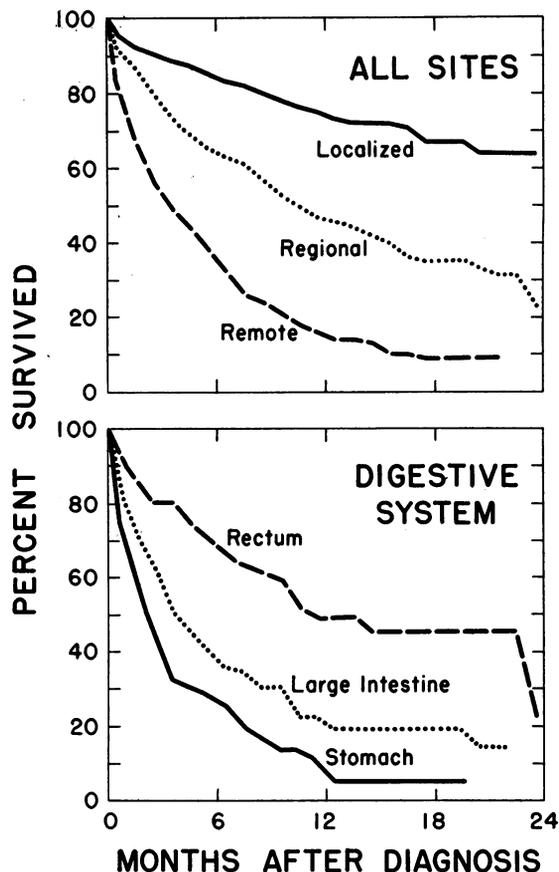


Figure 3. Survival experience of cases of cancer newly diagnosed during 1948 and 1949 in four Maryland counties, by stage at diagnosis and by selected site of cancer. (Survival for 24 months not shown in some instances, because of insufficient data.)

cause of death and for furtherance of knowledge of the disease, information was collected on whether or not an autopsy was performed for each death attributed to cancer. It was found that autopsies were performed in only 9 percent of cases in which cancer was reported as the cause of death. This percentage was even lower than the percentage of autopsies among deaths from all causes (12 percent).

Survival and Apparent Recovery

Rates of survival and apparent recovery from cancer are useful tools in measuring the success of cancer case management. Information on the probability of survival and recovery can also assist the physician in determining the optimum frequency of follow-up examination and the intervals within which the disease is most likely to recur.

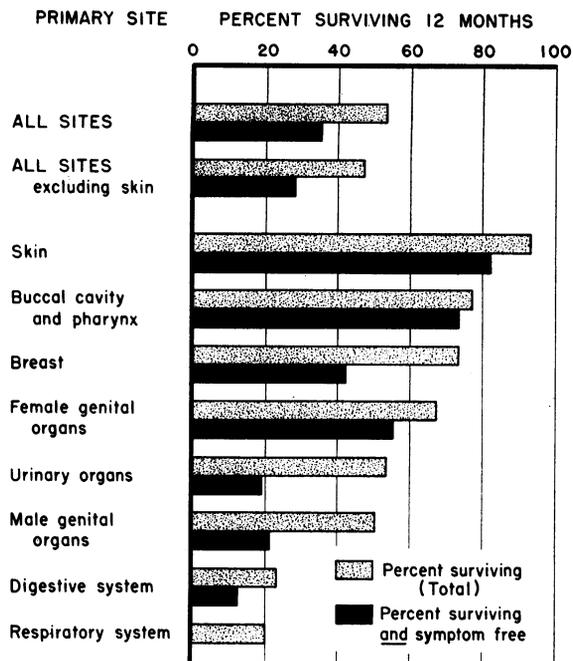


Figure 4. Comparison of total survival rates and symptom-free survival rates for cases of cancer newly diagnosed during 1948 and 1949 in four Maryland counties.

Calculated on the basis of a modified life table method, 53 percent of cases newly diagnosed with cancer in 1948 and 1949 survived 1 year after diagnosis; 37 percent survived 2 years. The rate of attrition was higher during the first several months after diagnosis than during subsequent months.

The chances of survival were considerably higher for females with cancer than for males—44 percent of females with cancer survived 2 years as compared to 28 percent of males. This difference is due principally to the larger proportion of cancers among males primary in sites with poor prognosis, such as the digestive and respiratory systems.

Survival rates by stage at diagnosis illustrate very strikingly the importance of early detection: 67 percent of cases diagnosed with a localized cancer survived 18 months compared to 35 percent for cases diagnosed with regional involvement and 9 percent for cases diagnosed

with remote or diffuse metastases (fig. 3). The lowest 18-month survival rates (5 percent) were among cases with cancer of the stomach (fig. 3). The survival rate of cancer of the respiratory system was also low (15 percent).

The 1-year survival rate of 53 percent for cases resident in the four counties is lower than the survival rate of 67 percent obtained for cases in the United States sample of five cities. To what extent this difference is a reflection of incomplete and selective reporting in the Maryland counties and to what extent the data represent true differences in survival experience of cancer cases cannot be determined at the present time.

The proportion of county cases diagnosed with cancer who were both alive and clinically free from cancer at the end of 1 year is estimated at approximately 35 percent (fig. 4). Thus, one might say that while half of all county residents who develop cancer will be alive one year after diagnosis, only one-third will be both alive and clinically free from the disease. All but 2 percent of those who die during the first year will die with cancer present at time of death.

Not only is there marked variation in survival rates by stage at diagnosis, there is also considerable variation in the proportion who are symptom-free among the survivors. The proportion of newly diagnosed cases alive and symptom-free at the end of 1 year represented 59 percent of the cases discovered while localized, and 23 percent of those diagnosed after regional metastasis.

Differences in survival and apparent recovery by cancer site and by county are shown in the detailed report. However, the relatively small number and selection of reported cases makes it unwise to consider these data as conclusive of true differences in survival experience. It appears essential to continue the collection of data on this and other aspects of cancer illness in the four counties.